Health Technical Services Project

Discussion Papers on
HIV/AIDS Care and Support

Responding to the Needs of Children Orphaned by HIV/AIDS

Prepared by
Susan Hunter and John Williamson

Discussion Paper Number 7

June 1998

UNITED STATES AGENCY FOR INTERNATIONAL DEVELOPMENT

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About HTS

The Health Technical Services Project provides short- and medium-term technical assistance to USAID — specifically, to regional bureaus, regional and country missions, and the Office of Health and Nutrition in the Center for Population, Health and Nutrition of the Bureau for Global Programs, Field Support, and Research (G/PHN/HN). This technical assistance supports USAID programs in maternal and child health, nutrition, health policy reform, HIV/AIDS, and environmental health. HTS activities are concentrated in three broad technical areas: project design, policy and strategy, and evaluation and monitoring.

HTS's work is grounded in the four complementary values that guide USAID's efforts to reengineer its operations:

- a customer focus
- participation and teamwork
- empowerment and accountability
- management for results.

Foreword

The U.S. Agency for International Development seeks to develop and promote effective strategies for providing basic care and support to those affected by HIV/AIDS. This series of Discussion Papers on HIV/AIDS Care and Support represents a first step in this effort.

HIV/AIDS care and support mitigate the effects of the pandemic on individuals, families, communities, and nations. Such interventions are an important component of the overall response to HIV/AIDS because they increase the impact of prevention strategies and mitigate the negative consequences of the epidemic on the prospects for sustainable development.

This series of Discussion Papers covers several key issues related to care and support:

- Human rights and HIV/AIDS
- Palliative care for HIV/AIDS in less developed countries
- Preventing opportunistic infections in people infected with HIV
- Psychosocial support for people living with HIV/AIDS
- Community-based economic support for households affected by HIV/AIDS
- Responding to the needs of children orphaned by HIV/AIDS
- Systems for delivering HIV/AIDS care and support.

Each paper provides a preliminary review of some of the current thinking and research on these broad and complex topics. It is important to note that the papers are not meant to be comprehensive — time and resource constraints prevented the authors from reviewing all the relevant literature and from contacting all the people who have valuable experience in these and related fields. Nor have they been subject to technical or peer review. Their purpose is to stimulate a broad conversation on HIV/AIDS care that can help USAID define its future program activities in this area. We welcome your participation in this process.

Two additional papers on the topic of voluntary counseling and testing were prepared with USAID support:

- The Cost Effectiveness of HIV Counseling and Testing
- Voluntary HIV Counseling and Testing Efficacy Study: Final Report

These two papers are available from the IMPACT Project, Family Health International, 2101 Wilson Boulevard, Suite 700, Arlington, VA 22201; www.fhi.org.

Please direct your requests for copies of papers in the Discussion Series on HIV/AIDS Care and Support and your comments and suggestions on the issues they address to the Health Technical Services (HTS) Project, 1601 North Kent Street, Suite 1104, Arlington, VA 22209–2105; telephone (703) 516-9166; fax (703) 516-9188. Note that the papers can also be downloaded from the Internet at the HTS Project's web site (www.htsproject.com).

—Linda Sanei, Technical and Program Advisor,
Health Technical Services Project

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Responding to the Needs of Children Orphaned by HIV/AIDS

The growing number of orphans in countries hard-hit by HIV/AIDS suffer a variety of deprivations and vulnerabilities. These include the loss of their families, depression, increased malnutrition, lack of immunizations or health care, increased demands for labor, lack of schooling, loss of inheritance, forced migration, homelessness, vagrancy, starvation, crime, and increased exposure to HIV infection. Given the scale of the problems, the first line of response from the affected children, families, and communities will be insufficient. Recent experience suggests that five basic interventions strategies can help maximize the impact of local, community-based responses: strengthening the capacity of families to cope with their problems; stimulating and strengthening community-based responses; ensuring that governments protect the most vulnerable children; building the capacities of children to support themselves; and creating an enabling environment for the development of appropriate responses.

In the countries most affected by HIV/AIDS, there has been growing concern over the number of orphans, a problem that has increased largely as a result of the pandemic. It has been difficult to track this trend because there are few estimates of the number of orphans caused by AIDS and because those estimates that do exist often are not comparable from one country to another. However, the needs of these children and their growing numbers mean that governments, donors, nongovernmental organizations, religious bodies, and others concerned about child welfare must take this trend seriously.

According to the U.S. Census Bureau, 15.6 million children will have lost their mothers or both of their parents by 2000 in 23 countries heavily affected by HIV/AIDS. That number will increase to 22.9 million by 2010, largely as a result of the HIV/AIDS pandemic. Nineteen of these countries are in Sub-Saharan Africa, where by 2010 these orphans will comprise up to 8.9 percent of children under age 15. The sheer size of the population at risk for HIV/AIDS in Asia means that the problem of orphaning there will eventually eclipse that of Sub-Saharan Africa. The number of orphans will continue to grow in Latin America and the Caribbean, where the pandemic started later.

The Census Bureau has estimated the number of maternal orphans (children who have lost their mothers) and double orphans (those who have lost both parents) in 23 countries hard-hit by HIV/AIDS.[1] The number of orphans in these countries is projected to grow sharply, largely as a result of the epidemic. However, these figures do not convey the full impact of HIV/AIDS on children and families in these countries. In order to develop a fuller picture of this impact, the U.S. Agency for International Development (USAID) contracted two independent researchers to expand the Census Bureau estimates of maternal and double orphans to include the number of paternal orphans (children who have lost their fathers). When paternal orphans are included, the total number of orphans from all causes is projected to increase from 34.7 million in 2000 to 41.6 million in 2010 in these 23 countries (Hunter and Williamson 1998).

The growing number of orphans will have a profound impact on the societies in which they live. Orphans may suffer the loss of their families, depression, increased malnutrition, lack of immunizations or health care, increased demands for labor, lack of schooling, loss of inheritance, forced migration, homelessness, vagrancy, starvation, crime, and exposure to HIV infection. With orphans eventually comprising up to a third of the population under age 15 in some countries, this outgrowth of the HIV/AIDS pandemic may create a lost generation — a large cohort of disadvantaged, undereducated, and less-than-healthy youths. The threat to the prospects for economic growth and development in the most seriously affected areas is considerable.

The vulnerabilities of these children are increased by the geographic concentration of the HIV/AIDS pandemic — vulnerable children are cared for by vulnerable families

[1]This study includes 21 countries where urban seroprevalence — the percent of the population infected with HIV — is over or near 5 percent, as well as two countries for which sufficient data are available to estimate the effect of HIV/AIDS on mortality. A full list of the study countries appears in Annex A.

and reside in vulnerable communities. Many of the communities most affected by HIV/AIDS are impoverished and isolated. Left with little or no outside assistance, some have devised creative programs to identify and assist the needy families in their midst, and there are similarities among these community-based responses. For example, many include mechanisms for assessing the needs of families and for monitoring the welfare of affected children. Many also include labor-sharing arrangements for day care and nutrition centers, agricultural work and other income-generating projects, home repair, and home care for the ill and for orphans. Paradoxically, these community-based support systems may be the least visible but most cost-effective ways to help families affected by HIV/AIDS.

Our experience with orphaning as a social problem is limited. Historically, orphaning on a large scale has been a sporadic, short-term problem, caused by war, famine, and disease. HIV/AIDS has transformed orphaning into a long-term, chronic problem that will extend into the next century. The serious social and economic dislocation that will result from the large and growing proportion of children who are orphaned will require comprehensive, creative, and long-term solutions.

In a family affected by HIV/AIDS, the children face problems long before a parent dies. Psychosocial distress begins with the awareness that a parent is infected with HIV. Children begin to worry about what will happen, but cultural taboos against talking about the possibility of someone's death mean that they are unable to express their fears. A parent's illness also brings economic problems to the household.

These problems are not limited to children orphaned by AIDS, and so interventions should be targeted to communities in which children have been made vulnerable. Even so, within a community, care and support should be directed to those individuals who are most in need, and HIV/AIDS should not be a criteria by which communities decide which children to help.

Coupled with the displacement of children from other causes, including natural disasters, war, and genocide, the number of children without parents promises to be extraordinary in some countries. Even if development assistance were increased, which is unlikely, it will be inadequate to address the problem. New approaches — including policy innovations for women and children — must be developed within the next few years to nurture and develop local efforts to assist families and communities.

CONDUCTING A SITUATION ANALYSIS

There is no standard set of interventions to apply in a community affected by HIV/AIDS. Before policy or program responses can be initiated, those who would intervene must develop a working understanding of children's most serious problems and how they and their families are coping with them. These issues must be understood well enough to identify priority geographic areas, the most pressing problems within those areas, and appropriate interventions.

Conducting a situation analysis involves compiling and analyzing relevant quantitative data (e.g., demographic, epidemiologic, problem incidence, economic) and qualitative information (e.g., the views of people in the affected communities, of key informants, and of agencies working in affected areas). The analysis examines the main factors that affect the nature and intensity of problems and the coping capacities of those affected. The situation analysis provides the basis for planning effective action.

A situation analysis can be much more than a technical exercise. If key actors are involved, it can become an opportunity to generate commitment at all levels. The United Nations Children's Fund (UNICEF) has often taken a leadership role in collaborating with governments and other donors to conduct situation analyses of children and families affected by HIV/AIDS. Other key actors may include major NGOs and support groups of people living with AIDS. Communities are often willing and eager to work with national and international organizations, and in many cases, the activities of such groups attract additional outside interest.

INTERVENTION STRATEGIES

The first response to the problems caused by HIV/AIDS comes from the affected children, families, and communities themselves, not from government agencies, NGOs, or donors. However, given the scale of the problems and the fact that those hardest hit are often the most disadvantaged, this first response will be insufficient on its own. Additional assistance from governments, NGOs, and donors is crucial. Recent experience suggests that five basic interventions strategies can help national governments, NGOs, and donors maximize the impact of local, community-based responses.

1. Strengthen the capacity of families to cope with their problems.

When a household begins to feel the effects of HIV/AIDS, extended family relationships are its first safety net. Although families are under great stress, the extended family has *not* collapsed under the weight of the HIV/AIDS pandemic. Most families are still providing some level of care for the overwhelming majority of affected children. However, the customs and reality of caregiving for AIDS and trends in family structure in developing countries combine to place the greatest stress and responsibility on females in the family, both adults and children. Action is needed to empower women and maximize their access to economic resources, as well as to build basic infrastructure to reduce the demands on women's labor.

The most effective way to address the problems faced by children affected by HIV/AIDS is through programs and polices that enable families and households to cope more effectively. The capacities of these families and households to provide care continue to be undermined by HIV/AIDS, and these must be reinforced.

Many of the problems faced by households affected by HIV/AIDS are fundamentally economic. These households are generally struggling to make ends meet and suffer setbacks when a member falls ill or dies from AIDS, when a sick member returns home, or when they take in orphans. Poor households are often further impoverished when adult labor is reduced by illness and death or redirected into providing care. Funeral expenses alone can amount to a year's income, and families often exhaust their resources seeking care for the sick before they die. These setbacks can be only temporary if families have access to formal or informal credit mechanisms or find ways to generate additional earning capacity.

There are various ways to improve households' income-generating capacity, but establishing women's lending and saving groups appears to be the most cost-effective, sustainable approach. Many microcredit programs worldwide have deliberately "packaged" their services to attract women clients because experience has shown that women are creditworthy and, as a rule, have excellent repayment rates. Experience has also shown that women are more likely to use income to help meet children's immediate needs. Households under the greatest economic stress are not likely to have the labor capacity to make effective use of credit, but improving the situations of those households that can participate in credit and lending programs may enable them to respond to the survival needs of their destitute neighbors.

In some situations, it may be appropriate to provide material inputs for specific activities such as gardening or raising livestock, if participants already have the necessary skills and access to resources and markets. However, efforts by outsiders to introduce unfamiliar income-generating initiatives typically incur significant costs and fare poorly. (Williamson and Donahue 1996)

In developing interventions to improve the capacities of households to generate income, it is important to recognize that the composition and vulnerabilities of these household differ and change over time, as do their capacities to make use of inputs. The potential of households to participate in and benefit from economic and other interventions depends to a large extent on how children and adults in various types of households use their time and whether they can make time for additional activities. This information can be obtained through observation, interviews, and focus groups.

Interventions that help reduce the demands on household members' labor can free them to undertake other productive activities. These might involve, for example:

- supporting community-based child care
- extending piped water to villages
- enabling artisans to produce fuel-efficient stoves to reduce the need for firewood.

Reducing "property grabbing" by protecting the property rights of women and children can reduce the vulnerability of AIDS survivors. In many parts of Sub-Saharan Africa, women and children are "owned" by the husband's family and therefore have no legal rights to own property on their own. After a man's death, relatives claim the husband's property, often citing their entitlements while ignoring their obligations under traditional law and leaving the widow and orphans with little or no means of supporting themselves. The situation may be further complicated by other traditional practices, including widows being "inherited" by a designated relative of the deceased husband, which can also spread HIV.

The welfare of widows and orphans generally depends upon their being able to stay in their homes and continue to use land and other property. Efforts to protect the property and inheritance rights of women and children may include:

- informing HIV–infected parents and women about laws that can protect their inheritance rights
- helping people to prepare written wills
- supporting legal services for widows and orphans to help them regain property

- sensitizing traditional leaders about the need to protect survivors' rights.

Children affected by HIV/AIDS face increased health risks. About a third of infants born to women who have HIV will themselves have the virus and are likely to develop AIDS much more rapidly than infected adults. Clinicians have had some success in reducing vertical HIV transmission (i.e., from mother to child) with the use of antiretrovirals and in improving the treatment of children infected with HIV. Unfortunately, most all women with HIV infection live in developing countries, where access to such treatments is virtually nonexistent (Mann and Tarantola 1996; UNAIDS 1997). The challenge for the future is to develop and deliver interventions to women in the poorest countries.[2]

Children living in households with an HIV–infected member may be exposed to tuberculosis, pneumonia, diarrheal diseases, respiratory infections, or other opportunistic illnesses. As AIDS morbidity and mortality erode family incomes, children's nutritional intake declines, and their families become less able to pay for needed health services. Research has shown that children in AIDS–affected households are less likely to be completely immunized. Poverty also increases children's vulnerability, and may induce them to exchange sex for money or material items as a coping strategy.

Measures that can reduce the health risks to children in HIV/AIDS–affected households include:

- developing community-based home health services for households caring for AIDS patients using volunteer and NGO networks
- expanding and supporting community-based child nutrition programs in more seriously affected communities
- reducing or waiving health care fees for orphans and other especially vulnerable individuals
- making special efforts to include orphans and other children at high risk in immunization programs and other health outreach efforts
- incorporating training about prevention of HIV infection in programs that reach children generally (e.g., at school) and in activities for especially vulnerable children (e.g., street children).

[2]See also the discussion paper in this series on human rights and HIV/AIDS (Lazzarini 1998).

- improving access to safe water in more seriously affected communities.

Protracted illness and the eventual death of parents have profound psychosocial effects on children, but these receive less attention than the more visible problems they face. Parents who are sick or who care for ill family members while supporting a household are less able to nurture and care for their children. The denial and silence that surround an impending death increase children's fears but prevent them from expressing them. The eventual death of a parent is profoundly traumatic and may leave serious, if invisible, scars. Children may be separated from their siblings to live in different households. They may feel shame from the stigma and discrimination associated with AIDS. Children deprived of normal socialization may grow into angry, disaffected youths who are receptive to opportunities for criminal or socially disruptive behavior.

Most measures to address the psychosocial needs of children affected by HIV/AIDS do not require separate new programs, but can and should be incorporated into school, health, and other activities. Infected parents should be helped to play normal parental and social roles and to give children opportunities to talk about their fears and to be supported. Examples of possible activities to address the psychosocial needs of parents and children include:

- outreach measures to support home-based care to help reduce the stress on affected families by meeting their physical needs
- counseling parents to talk with their children about their illnesses and their futures
- training teachers to recognize classroom behaviors that reflect emotional distress and providing supportive counseling and activities outside the classroom (e.g., sports) for these children
- improving the listening and counseling skills of community volunteers who are monitoring the welfare of orphans
- organizing ongoing group recreation programs in communities heavily affected by HIV/AIDS
- arranging standby guardianship to help ease the minds of both parents and children
- ensuring appropriate, effective placement services reach children without adult care, including some assurances that strong efforts will be made to keep siblings together.

- supporting measures to reduce the stigma and discrimination associated with HIV/AIDS.

2. Stimulate and strengthen community-based responses.

For children whose families cannot adequately provide for their basic needs, the community is the second safety net. The types of spontaneous, community-based interventions discussed previously can help care for children who remain in families under great stress. They can also help children who must leave their families retain ties of kinship and community.

The most vulnerable children and families are the least to make their needs known to other members of the community. An active effort is required to identify them and to mobilize local resources to respond to their most urgent needs. Assisting communities in developing and implementing assistance programs involves respecting community decision-making and enhancing their ability to target assistance to vulnerable families. Such efforts may also involve providing microcredit, seeking to protect women's and children's property rights, and providing training.

Examples of programmatic interventions that can help enhance the ability of communities to respond to HIV/AIDS and to maximize the impact of their efforts to do so include:

- enumerating orphans and assessing needs to determine the extent of the problems
- identifying families and children in need of external assistance
- monitoring the condition of vulnerable children and families
- sharing labor for many types of projects, including cooperative day care to free single parents to work, agricultural projects at various levels to increase output, income-generating projects to produce food and cash, repairing deteriorated houses, providing home care and orphan visiting schemes, and making and distributing school uniforms.
- initiating credit schemes for funeral benefits and income-generating projects
- ad hoc and formal efforts to protect the property rights of widows and children
- providing vocational and other training to orphaned adolescents to give them marketable skills
- changing community requirements and fees for school and health services to minimize the burden on needy AIDS–affected families and children.

Many of these initiatives already have been tried by affected communities, often without external support. As noted, most have been implemented by community-based organizations (CBOs). Among the CBOs and individuals that can identify, monitor, and assist those affected by HIV/AIDS are religious bodies, schools, health centers, community elders, elected representatives, women's groups, civic associations, and groups specifically organized to respond to needy children.[1]

Providing support to programs launched spontaneously at the community level must be done with caution and must be guided by a participatory situation analysis. Outside assistance can help strengthen and sustain such volunteer efforts by providing small amounts of funding, material support, training, and recognition for volunteers. However, external support can change the nature of an initiative and undermine the community's sense of ownership, often with negative long-term effects. For example, making volunteers into salaried staff members may make it more difficult to sustain the activity beyond the period of external funding. In Uganda, the Community Based Association for Child Welfare (UCOBAC) developed a "grants bank" approach that enabled large donors to provide small amounts of seed funding to many community-based initiatives to benefit orphans while avoiding some of these destructive effects (UNICEF 1994).

3. Ensure that governments protect the most vulnerable children.

The most vulnerable children are those who fall through both safety nets. They need a third line of response. Under national law and the Convention on the Rights of the Child, national governments have the ultimate responsibility to ensure that children are protected and cared for if they are on their own or if those with whom they live are unable or unwilling to care for them.

This requires governments to intervene to protect abused or neglected children. It also involves a responsibility to provide services on many levels that improve the welfare of children, including ensuring access to safe water and health services, enabling all children to attend school, and empowering families to support themselves economically.

[1]Many examples of community-initiated projects are described in UNICEF (1994).

Children who lose parental care are extremely vulnerable. Those who live on their own, with no adult caregiver, are at exceptional risk of exploitation or abuse, whether they remain in their own homes and villages or turn to city streets.

In addition to orphaning, infant abandonment has increased in some countries where HIV–positive mothers face poverty, stigma, and a lack of family and community support, Kenya and the Dominican Republic (UNICEF 1994). It is important to understand that, while all infants born of HIV–infected mothers receive HIV antibodies, only about a third are actually infected with the HIV virus. Some of the basic, tests for HIV actually detect the presence of antibodies to the virus, rather than the virus itself. Without more sophisticated testing, the HIV status of children born to HIV–positive mothers may be uncertain. In some countries, abandoned infants who have tested positive for HIV (perhaps falsely) may be institutionalized if they are at very high risk instead of being placed in foster care.

Adoption and foster care mechanisms will be needed to help children in need of special placement. Building these mechanisms involves strengthening and expanding governmental or NGO foster care and adoption programs, supporting measures to ensure rapid placement of abandoned infants, and, where institutional care exists, supporting screening procedures to determine whether better placement options are available and that care meets appropriate standards.

Institutional placement is, at best, a last resort, to be used only on an interim basis until more appropriate placement can be arranged. Institutional care is not an acceptable solution to the growing problem of AIDS orphans because it generally fails to meet children's developmental needs, including opportunities for attachment and normal socialization. The younger the child, the more likely it is that placement in an institution will impair his or her psychological development. It is too expensive to provide on a large scale, and it tends to create more demand for child placement by poor families who are struggling to care for orphans.

Protecting children's property rights can reduce their vulnerability. Nonetheless, many children orphaned by AIDS have to work to survive, and they often find themselves in harmful or abusive situations. Children who exchange sex for money are extremely vulnerable and their health and safety are at serious risk. Children who work in other situations also jeopardize their health and safety. According to the UNDP, "child labourers are among the world's most exploited workers" because they cannot defend themselves against long hours for low pay and are forced to "sacrifice their health, their education and their childhood" to survive (UNDP 1993). The largest number of child laborers are in Asia, where they make up an estimated 10 percent of the workforce. Up to 20 percent of children are working in several countries in Africa,

and up to 25 percent are working in some Latin America countries (UNDP 1993). These proportions, which do not account for children who labor in domestic and family farm activities, are likely to increase as AIDS continues to decrease the number of adults in the labor force.

The effectiveness of measures to benefit working children will vary depending on the cultural context, legal framework, and responsiveness of government agencies. Key government measures to protect especially vulnerable children include:

- sensitizing police to the situations of children who work on the street and to the laws that protect them
- promoting strict enforcement of child labor laws
- supporting initiatives that provide less harmful ways for children to earn income
- working with employers to provide children safer conditions, shelter, education and training
- ensuring adequate child protection services are in place
- bringing national law into compliance with the United Nations Convention on the Rights of the Child
- facilitating NGO programs to provide shelter, care, and education for street children and to promote their social reintegration
- ensuring policies and services are in place to support culturally appropriate foster care and adoption.

4. Build the capacities of children to support themselves.

Orphans often must support themselves and their younger siblings. AIDS catches children in a double bind. At a point where children face a premature need for education and training that will help them support themselves, economic pressures and the need to replace lost adult labor often force them to drop out of school. Girls are often forced to drop out first, causing long-term health loses for the society. Research has shown that gains in female educational levels correlate with reduced infant and maternal mortality (World Bank 1993). Even while AIDS is removing highly educated and skilled workers from the labor force, it is forcing the children and young adults who could replace them to leave school, increasing their poverty, frustration, and social disaffection.

Enabling children to stay in school or to be offered vocational training improves their ability to provide for their own needs, now and in the future. Interventions to help children continue their education must address the specific factors that cause them to drop out. Some children have to care for sick parents or replace lost adult labor at home. Others are unable to pay school fees or buy uniforms, books, and supplies because of their family's economic decline. In some cases, families (perhaps rightly) do not consider education to be a sufficient investment to make the sacrifices needed to keep children in school. Stigma and discrimination keep some children out of school. Interventions to address these issues may include paying school expenses or vocational training fees, increasing the relevance of educational programs, supporting apprenticeships with local artisans, constructing school facilities in exchange for guaranteed admission of orphans, and developing schools without walls for part-time students.

It is also important to decrease households' dependence on children's work. As noted above, this may include including initiatives to boost the income-generating capacity of poor households affected by HIV/AIDS; water, fuel, or other projects that reduce household work requirements; and respite care for people with AIDS.

Each approach has strengths and limitations. The most directly effective methods, such as paying school fees, are not sustainable, particularly when the numbers of children affected becomes very large. Indirect measures, such as providing credit to increase household income-generating capacity, are more sustainable but may be insufficient in areas where school expenses are high. One priority measure, of course, is to protect children from exploitation and abuse.

5. Create an enabling environment for the development of appropriate responses.

The best efforts of children, families, and communities to help themselves will be wasted if they are not enabled to optimize the use of their resources for prevention, care, and survival. This requires collaboration among all government ministries, donors, NGOs, and community groups concerned with the welfare of children and families.

In many Sub-Saharan African countries, responsibility for children's welfare is often assigned the most under-staffed and under-funded government agencies. Resource-strapped governments also rely on funding and assistance from donors and NGOs to provide many health, educational, and social services. Collaboration among these

agencies and organizations is essential to improving the effectiveness and sustainability of community-based responses to HIV/AIDS.

Such collaboration can create an environment that ensures and improves the welfare of children and families. It can also help ensure that programmatic interventions are cost-effective and sustainable.

Policymakers, community leaders, journalists, employers, and the public at large must be made better aware of the problems facing children affected by HIV/AIDS. This can be done through conferences, efforts to attract media attention to the issues, and public information campaigns about the impact of HIV/AIDS and about how some communities are responding.

Stigma and discrimination impede efforts to prevent the spread of HIV, improve care and support of those with AIDS, and reduce the effects on their family members. The process of reducing stigma and discrimination is largely one of reducing fear, ensuring basic legal protection, and transforming the public perception of HIV/AIDS from "their problem" to "our problem." Providing information and challenging myths can help reduce fear. Laws to protect the rights of those with HIV and their families regarding health services, employment, housing, and schools can directly enhance their ability to cope. In some countries, attitudes have been changed by political leaders and popular public figures, and religious bodies have established ongoing programs to promote awareness and compassionate action.

Several mechanisms can be instituted to improve coordination and increase the effectiveness of intervention programs. These include a regular forum for key actors to come together regularly to share information, coordinate activities, and build partnerships; clearly defining roles for governmental and nongovernmental actors; developing policies that define strategic approaches, programming priorities, and geographic responsibilities; and coordinating donor activities.

Appropriate programs generally meet three criteria:

- They should be effective, making a significant impact on priority problems.
- They should be cost-effective, with a reasonable cost per beneficiary.
- They should be sustainable over the long term.

Because an HIV/AIDS epidemic is constantly evolving, monitoring the epidemic and its effects provides essential information to guide policy and program development.

Systems that regularly collect and disseminate information on health and socioeconomic impact of AIDS on families and children are particularly important.

The private sector's commitment to respond should be nurtured. Many countries have work-site AIDS prevention programs with nascent care components. In some countries, concerned employers are developing survivor support programs which include health, education, and vocational training. Private philanthropy can also be a source of support for local programs.

Laws and policies should be changed, where necessary, to reduce the vulnerability of children and families. Key issues include protection and placement for children without adequate care; inheritance and property rights for widows and orphans; protection against abuse, neglect, and sexual contact with adults; prohibition of harmful child labor; protection of street children; gender equity; and elimination of barriers to orphans staying in school. Several countries in Africa have developed polices concerning orphans, defining ministerial responsibilities and calling for family and community-based care with institutional placement only as a last resort.

Even the best laws and policies will have little or no impact if governments lack the commitment and capacity to enforce them. Donors, in addition to advocating constructive laws and policies, should consider supporting training and technical support for key ministry personnel, as the USAID mission has done in Uganda (Williamson, Adugna, and Jones 1994). In addition to measures specifically targeting problems among orphans and other vulnerable children, government ministries should also give attention to using other development and health initiatives to bolster the coping capacities of families and communities affected by HIV/AIDS. On some issues, local policy may be more easily changed than national policy. Action in the policy arena may also address the broader health or democracy-building objectives of individual USAID missions.

National leaders must be encouraged to help shape potentially contentious family policy. In Uganda, for example, issues pertaining to families affected by AIDS were widely debated in the state-sponsored newspaper, and an alliance between the government and NGOs was formed to build local capacity. Malawi formed a national policy making group for orphans in 1991, which continues to operate under the Ministry of Women, Youth, and Community Services.

A report from the Population Council identified areas that governments should consider in family policy (Bruce et al. 1995). Some of these are summarized below.

- Government planning for child welfare: Thanks to economic adjustment policies and other trends, "governments are not making sufficient investment in the next generation or in adults who wish to be good parents" (Bruce et al. 1995). Governments need explicit policies on child rights, clear plans and policies for investing in children, and clear plans for dividing responsibility between private sources and the state. In the wake of AIDS, more responsibility may have to be assumed by the state for children's education, health, and social welfare because parents' ability to provide these is declining. Government need to find ways to make these services cheaper and more efficient.

  Historically, if child rights are articulated at all, they are implicit in parents' rights, especially those of mothers. Most governments have adopted the Convention on the Rights of the Child, but it is implemented with varying degrees of success. Children are entitled to a fair share of their parents' resources, regardless of their marital status. "It is not sufficient to treat the support and socialization of children as a purely private issue" (Bruce and Lloyd 1992).

- Gender equity: Policies and plans should promote a realistic balance of responsibility between both parents, so that men are held responsible for their children and for multiple wives and so that care becomes a necessary and honorable task for both men and women. "Longstanding marriage patterns [such as polygamy], functional in their time, potentially penalize children in modern economies" (Bruce et al. 1995). In many countries, policies that define what happens to children in the event of marital dissolution or when a marriage is not formalized need to be defined. "Many countries have not evolved a framework of law that provides adequate protections against loss of land, housing or income to adults who have custody of children" (Bruce et al. 1995).

- Family realism: Societies need to support families as they really are, not as they imagined them to be. This becomes more important as AIDS changes the composition of many families.

- Reproductive choice and rights: Family policy can include reproductive choice and rights, including the right of women to chose parenthood voluntarily, to be informed about their choices, and to have access to methods of averting parenthood and disease.

- Creating new norms for young people: Family responsibilities must be understood by young people so that they can engage in discussions and debates about responsible sexual behavior and marital/partner responsibilities.

- Fitting work and family together: A comparative study suggests that of the wide range of work-related policies that could help households headed by single women, those that help make child care more accessible and affordable are the most important. In some areas, efforts to do this have developed spontaneously, such as women's voluntary associations in Uganda. Other important workplace issues include parental leave and informal arrangements with employers that allow women to take over the work of their dead spouses. As noted above, alleviating women's burdens of domestic work and care can help free up their time for income-generating activities. Some beneficial changes may come about readily as employers seek to address labor shortages resulting from increased AIDS mortality (although these shortages will also require vigilance against exploitation of child labor).

- Targeted economic development: "Economic shifts...can produce a rapidly rising proportion of economically disadvantaged families with children. Under such circumstances a geographically targeted economic development plan may be the best fundamental family policy" (Bruce et al. 1995).

- Community support. Community services that support poor and isolated parents would help alleviate the burdens on families affected by HIV/AIDS. In fact, "many countries are creating mechanisms to foster in modern urban settings the collective caring for children that often characterizes traditional rural life" (Bruce et al. 1995, 111), although these may be more difficult to develop in very low-income urban settlements. One example is Guardianship Councils in Brazil, which are community councils that monitor children's rights and coordinate the delivery of services. These types of programs also have sprung up spontaneously in many areas with high AIDS mortality in Africa, often with the support of employers. NGOs skilled in promoting the transfer of initiatives from community to community have set up some good models.

- Women's role and status: The same families that rely upon women to assume ever-growing responsibility for family support and to function as good wives and mothers undermine women in their efforts to fulfill these roles. Abuse of family-based power—in particular, destructive abuses of husbands' superior strength and access to resources—demote women from partners in marriages to juniors in marriage, from effective advocates for their dependents to dependents themselves. These undermining family forces are frequently reinforced in the wider social arena. Women are treated under some systems of family law more as property than as free adults. Women's economic claims are regularly ignored by policy, leaving them doubly discriminated against on the basis of their gender and their normatively ascribed family roles.

The importance of women's role as caregivers for HIV/AIDS patients and as heads of households affected by AIDS cannot be overemphasized. Policies and programs must be developed to ensure and support women's ability to make a livelihood and that accommodate their special family responsibilities. Also, women's access to resources, including labor and markets, should not be dependent on their relationships to men or to their fertility status. Policies that make it necessary for women to get a man's permission to get credit or that prevent them from owning property should be reversed.

Prevailing cultural norms can intensify inequalities, including domestic violence, physical and sexual abuse, abortion laws and practices, and women's social and political standing:

> changing the beliefs and contexts that foster discrimination is perhaps politically one of the most difficult challenges.... Such a concept will force policy leaders to stretch intellectually and to engage seriously in the original thinking and creative programming necessary to counter discrimination and link individual behavior with global outcomes. (Hamilton 1994)

In many countries, such policies have been codified into law, but their implementation has been hindered by conflicts with traditional law. Other countries are making an effort to get out in front of the epidemic by passing and enforcing legislation that reduces gender discrimination. For example, in 1990 Uganda raised the legal age of marriage and enforced it in a widely publicized case when a man in his sixties tried to buy a wife who was 12 years old; once they became aware of this, villagers drove the man off.

- Property and inheritance: In most African countries, women's property rights are not protected. In many areas, gender discrimination is enshrined in statutory law. These laws and practices need to be revised, and this is occurring. In some areas, for example, active local associations have controverted national law or developed their own policies to protect the rights of women and children.
- Child labor: Child labor is prevalent in many countries and will likely increase as a result of AIDS. Efforts to protect children from harmful work situations must involve clear government policies and a demonstrated commitment to enforce them. These should be reinforced by government efforts to mobilize public support and by programs that help children and their families meet their economic needs.

Annex A: Study Countries

Nineteen of the countries included in the study from which this paper was drawn (Hunter and Williamson 1997) were selected because their seroprevalence — the percent of the population infected with HIV — was estimated to be greater than 5 percent in urban areas. Four additional countries are included: two where seroprevalence is approaching 5 percent; and two for which there were sufficient data to estimate AIDS mortality and orphaning rates.

East Africa
Burundi
Ethiopia
Kenya
Rwanda
Tanzania
Uganda

Southern Africa
Botswana
Lesotho
Malawi
South Africa
Zambia
Zimbabwe

West and Central Africa
Burkina Faso
Cameroon*
Central African Republic
Congo
Côte d'Ivoire
Democratic Republic of the Congo
(formerly Zaire)
Nigeria*

Outside Africa
Brazil**
Guyana
Haiti
Thailand**

* Seroprevalance approaching 5 percent.

** Seroprevalance less than 5 percent, but sufficient data available to estimate mortality using special modeling scenarios.

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Annex C: Acronyms

Below is a list of the acronyms used in this report.

CBO	Community-based organization
HIV/AIDS	Human immunodeficiency virus/acquired immunodeficiency syndrome
HTS	Health Technical Services Project
NGO	Nongovernmental organization
STI	Sexually transmitted infection
UCOBAC	Community Based Association for Child Welfare (Uganda)
UNICEF	United Nations Children's Fund
USAID	United States Agency for International Development

Annex D: Prevention and Care Dynamic of Interventions to Assist Children Orphaned by HIV/AIDS

Figure 1. Prevention and Care Dynamic of Interventions to Respond to Children Orphaned by AIDS				
Intervention	**Immediate Beneficiary**	**Primary Benefit**	**Mitigating Effect**	**Prevention Benefit**
1. Strengthen the capacity of families to cope with problems P Increase families' resources P Provide temporary credit P Increase families' income P Reduce demands on families' labor P Protect women's and children's property rights P Ensure access to health services P Meet psycho-social needs	Families and extended families affected by HIV/AIDS	Reduces families' economic vulnerability to setbacks caused by illness or death related to HIV/AIDS	P Protects the welfare and nutritional status of women and children in HIV/AIDS–affected households P Reduces the health risks and psychosocial distress suffered by children affected by HIV/AIDS	P Prevents economic destitution that can lead children to exchange sex to meet their income or material needs P Alleviating material problems or psychosocial distress may increase receptivity to prevention messages

Figure 1. Prevention and Care Dynamic of Interventions to Respond to Children Orphaned by AIDS				
Intervention	**Immediate Beneficiary**	**Primary Benefit**	**Mitigating Effect**	**Prevention Benefit**
2. Stimulate and strengthen community-based responses P Respect community decisions P Provide microcredit P Protect women's and children's property rights P Provide training	Children whose families cannot adequately provide for their basic needs	P Provides care to children who are in families under great stress P Helps children who must leave their families retain ties of kinship and community	P Meets the survival needs of vulnerable children and families P Increases earning potential of adolescents and families P Pools labor, freeing resources for income-generation, caring for sick family members, or caring for children P Keeps children in school P Increases social integration of those living with or affected by HIV/AIDS	P Reduces the vulnerability of orphans and other children to poverty, ill health, and risk of HIV infection P Raises awareness of HIV/AIDS Impacts P Provides opportunities to convey information on prevention P May increase receptivity to prevention messages

Figure 1. Prevention and Care Dynamic of Interventions to Respond to Children Orphaned by AIDS				
Intervention	**Immediate Beneficiary**	**Primary Benefit**	**Mitigating Effect**	**Prevention Benefit**
3. Ensure governments protect the vulnerable children **P** Protect abused or neglected children **P** Build adoption and foster care mechanisms **P** Protect children's property rights **P** Protect working children	Protect children who fall through family and community safety nets	**P** Improves the welfare and ensures the human rights of children on their own or living with people who are unable to care for them **P** Enables vulnerable children to live in safer, healthier circumstances	Meets the urgent health and safety needs of orphans and abandoned and neglected children	**P** Protects children from exploitation or abuse, which can increase their risk of HIV infection **P** Improves access to marginalized children for promoting prevention
4. Build capacities of children to support themselves **P** Enable children to stay in school **P** Reduce demands on family labor **P** Protect children from exploitation	Children who have dropped out or are at risk of dropping out of school and/or training	Improves children's ability to provide for their own needs now and in the future	Reduces economic pressures that can for children to drop out of school and thereby jeopardize their future earning potential and health	**P** Reduces poverty and attendants risks of exploitation, abuse, and ill health, including exposure to HIV **P** Improves access to vulnerable children through schools and training programs

Figure 1. Prevention and Care Dynamic of Interventions to Respond to Children Orphaned by AIDS				
Intervention	**Immediate Beneficiary**	**Primary Benefit**	**Mitigating Effect**	**Prevention Benefit**
5. Create enabling environment for appropriate responses P Increase awareness, understanding, and commitment P Reduce stigma/ discrimination P Increase program impact P Monitor epidemic P Nurture private sector response P Change laws, policies, and actions	Children and families to affected by HIV/AIDS	Improves the ability of children and families to cope more easily with the effects of HIV/AIDS	P Optimizes use of family resources for HIV/AIDS prevention and care and for survival P Directs more resources to HIV/AIDS prevention and mitigation P Improves protection of human rights and access to services	P Reduces stigma and discrimination that can impede prevention efforts P Improves cost-effectiveness and sustainability of program interventions